DOCUMENT RESUME

ED 179 319 PS 011 067

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TITLE Meeting the Educational Needs of Children with Cancer.
SPONS AGENCY National Cancer Inst. (NIH), Bethesda, Md.
PUB DATE Sep 79
GRANT 1R18CA2527101; 2R18CA17806
NOTE 24p.; For related documents, see PS 011 000-001 ; Some pages marginally legible due to faint type

EDRS PRICE MF01/PC01 Plus Postage.
DESCRIPTORS Academic Achievement; Attendance; *Attendance Patterns; *Cancer; Children; Educational Improvement; Elementary Secondary Education; *Exceptional Child Education; Health Personnel; Hospitalized Children; *Interinstitutional Cooperation; *Intervention; *Patients (Persons); Rehabilitation; School Personnel

ABSTRACT

This paper provides information concerning the school experience of children with cancer and describes a program of intervention by the pediatric psychologist and the oncology nurse-clinician to facilitate the child's successful return to school. School records, including attendance, grades, standardized test scores and teachers' comments, were collected on a group of 116 children currently in treatment for cancer at the University of Kansas Medical Center. Among these patients, the most frequent problem was absenteeism. The high rate of absenteeism was associated with other school difficulties, including declining grades (18.1% of the sample) and failing grades (10.6%). Over 10% of the children had behavior problems (e.g. inattention, acting out). An intervention program was developed to bridge the gap between the hospital and the child's home school. Procedures include: (1) an initial conference with school personnel; (2) printed material concerning the medical and psychological/social aspects of childhood cancer, (3) follow-up consultation as needed, and (4) program evaluation. Results of a pilot project involving 15 children showed that teachers and other school personnel significantly increased their factual knowledge about childhood cancer. Post-intervention attendance improved for those children who were medically able to go to school. Parents and teachers expressed satisfaction with the program. (Author/RH)

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ED179319

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# Meeting the Educational Needs Of Children with Cancer

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This investigation was supported by Grant Number 2R18Ca17806 and 1R18CA2527101, awarded by the National Cancer Institute, DHEW.

## Abstract

The most important single indicator of successful rehabilitation for children with cancer is their progress in school, for school is the work of children. Despite the importance of this area there is only minimal information concerning the school experience of cancer patients. This paper will present such data and describe a program of intervention by the pediatric psychologist and the oncology nurse-clinician to facilitate the child's successful return to school.

School records, including attendance, grades, standardized test scores and teachers' comments, were collected on a group of 116 children currently in treatment for cancer at the University of Kansas Medical Center. These children represent approximately 50% of the total patient population. Among these patients, the most frequent problem was absenteeism. Absenteeism was highest during the year in which the child's illness was diagnosed (mean days missed = 41.1). Even in the third year after diagnosis, half of the children in school at that time missed more than 17 school days.

The high rate of absenteeism was associated with other school difficulties, including declining grades (18.1% of the sample) and failing grades (10.6%). Over 10% of the children had behavior problems (e.g. inattention, acting out).

An intervention program was developed to bridge the gap between the hospital and the child's home school. Procedures include: (1) an initial conference with school personnel; (2) printed material concerning the medical and psychological/social aspects of childhood cancer, and (3) follow-up consultation as needed. Program evaluation includes pre- and post-intervention questionnaires completed by parents and school personnel as well as comparison of the children's school performance before and after instituting the inter-

# Meeting the Educational Needs of Children with Cancer

Advances in pediatric cancer therapy have enabled most children with cancer to return to their homes, schools, and communities. Childhood cancer has become a chronic disease which need not prevent a child from living a normal or near-normal life much of the time. Therefore, total treatment demands that we look at not only the length of survival with cancer but also the quality of the child's life after diagnosis.

The educational needs of children with cancer have received some recent attention in the literature. Most authors agree that children with cancer need and can benefit from school (Lawson, 1977; van Eys, 1977). They also stress a high probability that these children will have difficulty in maintaining school attendance and achievement, because of the limitations imposed by the disease and because of the emotional implications of childhood cancer for patients, parents, and school personnel. However, despite an apparent recent upsurge of interest in this topic, no authors have presented specific data on the school experience of any sizeable or representative sample of children with cancer.

Futterman and Hoffman (1970) described a single case of transient school phobia in a child with leukemia. In our population at the University of Kansas Medical Center we have found a relatively high occurance of the school phobia. The incidence among the population at large is less than 1%. Among children with cancer, the incidence is more than 10% (Lansky, Lowman, Vats, & Cyulay, 1975). Cyphert (1973) reported a dearth of empirical evidence but nonetheless made a number of statements about educating children with

vention. Results of a pilot project involving 15 children are promising: teachers and other school personnel showed a significant increase in their factual knowledge about childhood cancer, post-intervention attendance improved for those children who were medically able to go to school, and parents and teachers expressed satisfaction with the program.

cancer. He stressed the importance of a productive learning experience, of treating the child "as near to normal as possible" (p. 215), and of encouraging the child to do "as much as he feels like doing," as did Holmes and Holmes (1975). He also discussed the emotional impact of cancer on the child's teacher, which may lead to the teacher's withdrawal from or isolation of the child with cancer (Cyphert, 1973). Greene (1975) and Kaplan, Grobstein, and Smith (1974) also described the problems stemming from teachers' lack of experience with these children, including incidents in which children have been refused the right to attend school because of their illness.

Several authors (Kaplan et al, 1974; Kirten & Liverman, 1977; Greene, 1975; & Wear & Blessing, 1976) offer suggestions for facilitating the child's return to school. Teachers need instruction about the child's diagnosis and treatment (Wear & Blessing, 1976; & Greene, 1975). Such instruction is necessary to counteract their lack of information and their frequently held misconceptions (for example, the relatively common fear that cancer is contagious). Teachers also need emotional support in handling their own fears and depression regarding the patient, and in communicating with the child's classmates about the illness (Kaplan et al, 1974). Both face-to-face contact (Cyphert, 1973; Greene, 1975) and dissemination of written information (Wear & Blessing, 1976) are said to be useful in helping school personnel meet the needs of the child with cancer.

The literature suggests that school problems occur. The present report is, to our knowledge, the first systematic study of a sizeable population of children. The objectives of the study were:

1. To present data on the school experience of a large group of children with cancer.
2. To describe a program of intervention to facilitate the child's academic career.
3. To present pilot data concerning the efficacy of the intervention program.

## Methodology

Subjects. Participants in this study were 116 school-aged children in treatment for cancer by the Division of Pediatric Hematology/Oncology at the University of Kansas Medical Center. Approximately one-third of the patients were diagnosed during their elementary school years, and the remaining 20% as adolescents. The patients were drawn from the states of Kansas (approximately 70%) and Missouri. Boys make up 60% of the group. The majority of the children had diagnoses of leukemia or lymphoma, with a smaller percentage having solid tumors (e.g. osteosarcoma, Ewings sarcoma). Only two of the children had brain tumors, which are usually treated by another department at our institution. (See Table 1 for further demographic details.)

Procedures. School records for all patients were routinely requested at the time of diagnosis or at the end of the child's first year of school. Records were updated at the end of each succeeding school year. We requested the entire cumulative records, including grades, attendance, standardized aptitude and achievement test scores, and teachers' comments.

Because the different schools use different grading systems, it

was necessary to express academic grades in a standard form which was comparable across students. We chose a 6-point scale, from 0 to 5, with 5 as the highest grade, 3 as average, 1 as failing, and 0 as incomplete or withdrawn from the course. This system fits the common A-to-F grading system. For schools using a 3-point system (e.g. Excellent, Average, Fail), the highest grade was given a value of 5 and the failing grade a value of 1, so that the 6-point range was maintained. A core grade point average was then calculated for each student for each year in school. Core subjects for elementary school students were Reading, Spelling, Mathematics, English, Social Sciences, Science, and Penmanship. Secondary school core subjects were Language Arts, Mathematics, Social Sciences, and Sciences. For purposes of evaluating attendance data, we used a 180-day year, the standard for both states.

Having assembled these data, we looked at three aspects of the children's school performance. First, we calculated the average and median days absent during the year of diagnosis and the three succeeding years. Second, we recorded the incidence of problems revealed in the records. These problems included absenteeism ($\geq$ 20 days per year); declining grades in one or more academic subjects; failing grades; behavior problems noted by the teacher such as inattention or acting out; and learning problems. Third, we looked at changes in core grade point averages between the year of diagnosis and the three subsequent years as compared to the year prior to diagnosis. These changes were calculated by subtracting the grade point average during the year in

question from the grade point average during the year prior to diagnosis. Negative change scores thus indicated decline in grades relative to the year before diagnosis.

## Results

The number of absences from school during the year of diagnosis and the succeeding years is substantial. Children in school when their disease was diagnosed missed, on the average, 41 days or two full months of school. In the three succeeding years, the average absences remained in the range of 25-35 days per year, well over a month of school days (see Figure 1).

The incidence of problems noted in the school records is shown in Figure 2. The most frequently encountered problem is a high rate of absenteeism, seen in two-thirds of the children. Nearly 20% of the children were noted to have some kind of behavior problem in school. The third most frequently encountered problem was decline in grades in at least one subject during one or more years. Eighteen percent of the children had this problem.

Changes in core grade point averages during the year of diagnosis and the year following diagnosis, as compared to the year prior to diagnosis, were not significant, Wilcoxon Signed-Ranks test for matched pairs, T=284, 253.5, and 113.5 for year of diagnosis and first two years after diagnosis, respectively; $p > .10$. However, there is a significant decline in core grade point averages by the third and fourth years after diagnosis, T+=17 and 10, respectively, $p < .03$.

Correlational analysis of school data suggests that, among elementary school students, there is a negative relationship between central nervous system irradiation and reading (and to a lesser extent, mathematics) grades (significant r values range from -.28 to -.68, $p < .05$). In addition, for older elementary students (grade 3 or higher) competence in reading and mathematics seems to increase as time since diagnosis increases (significant r values range from .27 to .35, $p < .05$). Among kindergarten students, longer time since diagnosis was associated with lower mathematics grades ($r = -.61$, $p < .05$), suggesting that children diagnosed at very young ages may be particularly at risk for academic difficulties.

## Discussion

The high rate of absenteeism and the frequency of significant problems found in the school records of this group of patients is most alarming. It is difficult to understand how a child who misses a month or more during a 9-month school year can maintain appropriate academic achievement, and in fact changes in core grade point averages do occur in the third and fourth years after diagnosis. It is difficult to know how to interpret the absences of decline prior to this point. On a significant percentage of the school records, teachers' comments suggest that the patients are graded more leniently than they were before diagnosis and more leniently than their classmates. Examples of these comments are "I always accept whatever he (the patient) is willing to give me," and "I hesitate to push him because I know he doesn't feel well." Therefore, it is possible

that these children's school grades are spuriously inflated to an unknown degree. This phenomenon has also been reported by Zwartjes (1979).

The importance of the child's school experience cannot be overestimated. School provides intellectual stimulation and preparation for productive adult life. It is the most significant, clearly measureable parameter of the child's rehabilitation. Furthermore, the total school experience is the arena in which the child's social ineraction takes place. Thus, children who are not in school, or who do poorly academically, are cut off from interpersonal as well as intellectual growth and development.

In view of this importance, we instituted a program to facilitate the child's re-entry into and progress in school. This intervention program basically consisted of establishing a relationship with the child's principal, teacher, and school nurse for the purpose of exchanging information and educating school personnel about cancer in children.

## Description of Intervention

Once informed consent was obtained from the child's parents, initial contact with the school principal was made. This contact usually took place prior to the child's return to school. The purpose of this contact was to introduce ourselves to the principal and arrange for a conference at the school with both school and medical personnel present.

An introductory letter and pre-intervention questionnaire were then sent to the child's teacher, principal, school nurse, and counselor. The questionnaire assesses general knowledge concerning pediatric cancer and therapy, attitudes toward cancer, expectations for the child with

cancer in the classroom and the respondent's need for information and/or support from medical center staff. These pre-intervention questionnaires provided baseline data against which the effectiveness of the intervention program could be evaluated.

The conference provided:

1. An opportunity for medical center personnel to render information concerning the child's disease, therapy and sequelae, prognosis and daily activities.
2. An opportunity for school personnel to inquire about the child's disease, therapy, prognosis, and school life - questions that they may feel uncomfortable asking the child's parents.
3. A setting in which the medical center and school personnel can cooperatively establish realistic and appropriate goals for the child's school career in spite of his disease, can identify potential problem areas, and can devise methods for dealing with problems.

At the end of the conference, the principal, teacher, counselor, and school nurse were supplied with the following written information:

1. A pamphlet "Cancer in the Classroom: How Do You Cope?" giving a general description of cancer in children, concepts of therapy, and potential problems that might be encountered in the classroom as well as suggestions for coping with these problems.
2. A list of all medical center personnel directly involved in the child's care including appropriate phone numbers where team members can be reached.

3. A reference packet for the school nurse containing specific information pertinent to the child's disease, drug therapy, any dietary requirements, and activity restrictions.

If it were impossible to visit the child's school in person because of distance (more than 40 miles from the medical center), then a conference call involving medical center and school personnel was arranged to take the place of the conference. All of the other interventions remained the same.

Consistent followup with the schools was necessary and quite helpful. Telephone contacts were made at least once each semester. Changes in the child's disease status and/or therapy were communicated to the school as needed. In addition, if other problems were uncovered in the course of the child's treatment (e.g. prolonged unexplained school absences) telephone contact and further conferences were arranged as needed.

Toward the end of the school year, the post-intervention questionnaire was sent to the same people who responded to the pre-intervention questionnaire. The purpose of the questionnaire was to assess the effectiveness of the intervention in educating school personnel about pediatric cancer and to assess the attitude of the school staff toward the intervention program. An additional questionnaire was sent to parents to ascertain their satisfaction with the program.

Occasionally, in spite of the above described intervention, a child continued to have severe or persistent school problems (e.g. lengthy unexplained absences from school). In these situations, even closer contact with the school personnel is necessary. Occasionally, additional conferences

or involvement of special services personnel may be indicated.

## Subjects

Eighteen children, 11 boys and 7 girls, have thus far participated in the intervention project. The children ranged in age from 5 years, 6 months to 15 years, 9 months. The boys and girls were comparable in age ($t(16) = -.5644$, $p > .50$). There were 14 elementary school students, two in junior high, and two in high school. Ten children were recently diagnosed at the time of intervention, 5 had been in remission for at least 6 months, and 3 had progressive metastatic disease and have since died.

## Results

### School Staff

Pre-intervention questionnaires were sent to and returned by the school personnel involved with 9 of these children. The school visits for the remaining 9 were arranged too hastily to permit sending pre-intervention materials prior to the school conference. Post-intervention questionnaires were sent to 16 of the 18 children. The remaining two school visits have occured too recently to obtain meaningful long-term followup data. Among the school personnel who responded to the questionnaires, there were 28 teachers, 12 principals, 8 school nurses, and 6 staff in other categories (e.g. nurse-aide, counselor).

Awareness of treatment modalities. The school staff's knowledge of the types of treatment the students receive (surgery, radiation, and chemotherapy), was virtually identical prior to and after our intervention. Over 90% of the respondents were aware of the children's chemotherapy,

two-thirds knew whether their student had undergone surgery, and less than one-half knew about radiation therapy.

The most frequently mentioned side effects of treatment, in both the pre- and post-intervention responses, were hair loss, nausea and vomiting, and increased susceptibility to infection. There were some differences in the frequency of expected versus observed side effects, as follows:

Fatigue: 12% expected this phenomenon; 56.4% reported observing it in the post-intervention questionnaires ($p < .001$).

Increased Appetite: None of the respondents reported this as a possible side-effect in the pre-intervention questionnaires, but 18.2% reported observing increase in appetite ($p < .05$). Similarly, only 12.5% of the respondents expected weight gain, while 25.4% observed it in their students (not statistically significant).

Weight Loss: Only 8.3% of pre-intervention questionnaire respondents mentioned weight loss; 40% reported that their students had lost weight by the time of the post-intervention questionnaire ($p < .005$).

Prognosis. Respondents were somewhat more realistic and more optimistic about the prognosis for childhood cancer by the time they answered the post-intervention questionnaire. In the pre-intervention questionnaire, while 80% of the respondents knew that childhood cancer can usually be controlled for significant periods of time, 12.5% thought that the disease

is invariably severely disabling and/or fatal. In contrast, 96% of post-questionnaire respondents recognized the likelihood of controlling the disease; almost half also noted the possibility of a fatal outcome.

Relapse/Remission. Of the four true-false questions concerning relapse and remission, only one - the definition of remission itself - revealed changes from the pre- to the post-intervention questionnaires. Only half of the respondents demonstrated an accurate understanding of remission in the pre-intervention phase. This figure rose to 80% of the post-intervention respondents ($p < .05$).

Attitudinal Factors. Several questions were asked concerning expected (pre-intervention) and observed (post-intervention) effects of the child's illness on his/her own behavior and that of the school staff and classmates. Concerning the patient, pre-intervention expectations of negative effects were not borne out in three areas. First, the patients experienced fatigue less often than expected ($p < .025$). Second, expected difficulty maintaining interest in school was observed very infrequently ($p < .025$). Finally, fewer patients than expected had to limit their physical education activities ($p < .005$).

Responses concerning effects on the teachers and classmates were virtually identical on the pre- and post-intervention questionnaires. Positive items were endorsed by the majority of respondents: teachers and students would be sympathetic and would benefit from the opportunity to learn about cancer. Approximately one-third of the respondents on both questionnaires felt that the patient received preferential treatment from school staff and/or peers.

Parent Questionnaires. Eleven parents (61%) returned their questionnaires. Their responses were almost invariably positive (Table 2). Nine of them reported that the school contacts had been "very helpful;" two reported that intervention was "somewhat helpful." Nonetheless, six of the parents reported that their children continued to have some problem in school. Absenteeism was encountered most frequently. Two children had some decline in grades, and one, because of a progressive CNS disease, had a decline in standardized achievement scores as well.

## Discussion

As the prognosis for children with cancer continues to improve, more and more of these children will be able to return to the classroom. We have learned that, without some help, significant numbers of these children will not get the full benefit from their educational experience. We have known children whose treatment has resulted in intellectual and social impairment despite recovery from their disease. Clearly it is necessary to treat the total child with attention to psychological as well as physical needs. For children, school is analogous to vocational pursuits in adults. Therefore, the child's academic progress is one of the most important and easily measurable indications of the success of rehabilitation.

The present study raises as many questions as it answers concerning how best to facilitate the child's academic progress. We have only preliminary data on the effectiveness of our described intervention program. While we have seen dramatic improvements in some children (e.g. patient D.B. who missed over 120 days in 77-78 year and missed

only ten days in the 1978-79 year), a large sample prospective study of grades and attendance, with control group, is just beginning.

We also need to evaluate the most efficient ways of educating and maintaining contact with school personnel. Audio- or video-tape may be as useful as and more efficient than face-to-face conferences. Inservice training and professional meetings may reach reach more people, but may not replace personal contact with the teacher of a newly diagnosed child. Another question concerns the best way of working with school personnel in outlying communities. In most cases, it is impractical for treatment center personnel to travel more than 40 miles to make a school visit. Use of conference telephone calls and recruiting and educating local community health nurses to work with these children are avenues which are being explored.

Finally, our experience raises the possibility of different responses by different school staff. It is still too early to make firm conclusions, but the data suggest that school nurses, to whom principals, teachers, and parents look for guidance, are less well informed than non-medical staff. These nurses are not usually aware of recent advances in pediatric cancer treatment and are, therefore, unduly pessimistic. Some are also confused about the meaning of remission, the implications of relapse, etc.. We need to pay particularly close attention to re-educating school nurses, who may not be at all familiar with cancer in children.

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Table 1

Demographic Data

| Variable | | Frequency | Percent |
|---|---|---|---|
| Sex | Girls | 47 | 40.5 |
| | Boys | 69 | 59.5 |
| Grade At Diagnosis | Kg or Before | 40 | 35.1 |
| | 1 | 13 | 11.4 |
| | 2 | 7 | 6.1 |
| | 3 | 12 | 10.5 |
| | 4 | 4 | 3.5 |
| | 5 | 8 | 7.0 |
| | 6 | 8 | 7.0 |
| | 7 | 4 | 3.5 |
| | 8 | 7 | 6.1 |
| | 9 | 5 | 4.4 |
| | 10 | 2 | 1.8 |
| | 11 | 1 | 0.9 |
| | 12 | 3 | 2.6 |

| Variable | | Frequency | Percent |
|---|---|---|---|
| Ordinal Position | 1 (Oldest) | 51 | 45.5 |
| | 2 | 26 | 23.2 |
| | 3 | 16 | 14.3 |
| | 4 | 12 | 10.7 |
| | 5 | 2 | 1.8 |
| | 6 | 3 | 2.7 |
| | >6 | 2 | 1.8 |
| Public School | | 105 | |
| Private/ Parochial School | | 9 | |

Table 2

Parent Questionnaire Responses

How helpful was the School Conference for your child?

9 Very helpful

2 Somewhat helpful

0 Did not matter

0 Made things worse

Has your child had any of the following problems? (check all applicable)

6 Absent from school more than 50 days

2 Decline in grades

1 Decline in standardized achievement scores

2 Decline in interest in school

1 Other

FIGURE 1

MEAN AND MEDIAN DAYS ABSENT FROM SCHOOL
DURING YEAR OF DIAGNOSIS AND THREE SUCCEEDING YEARS

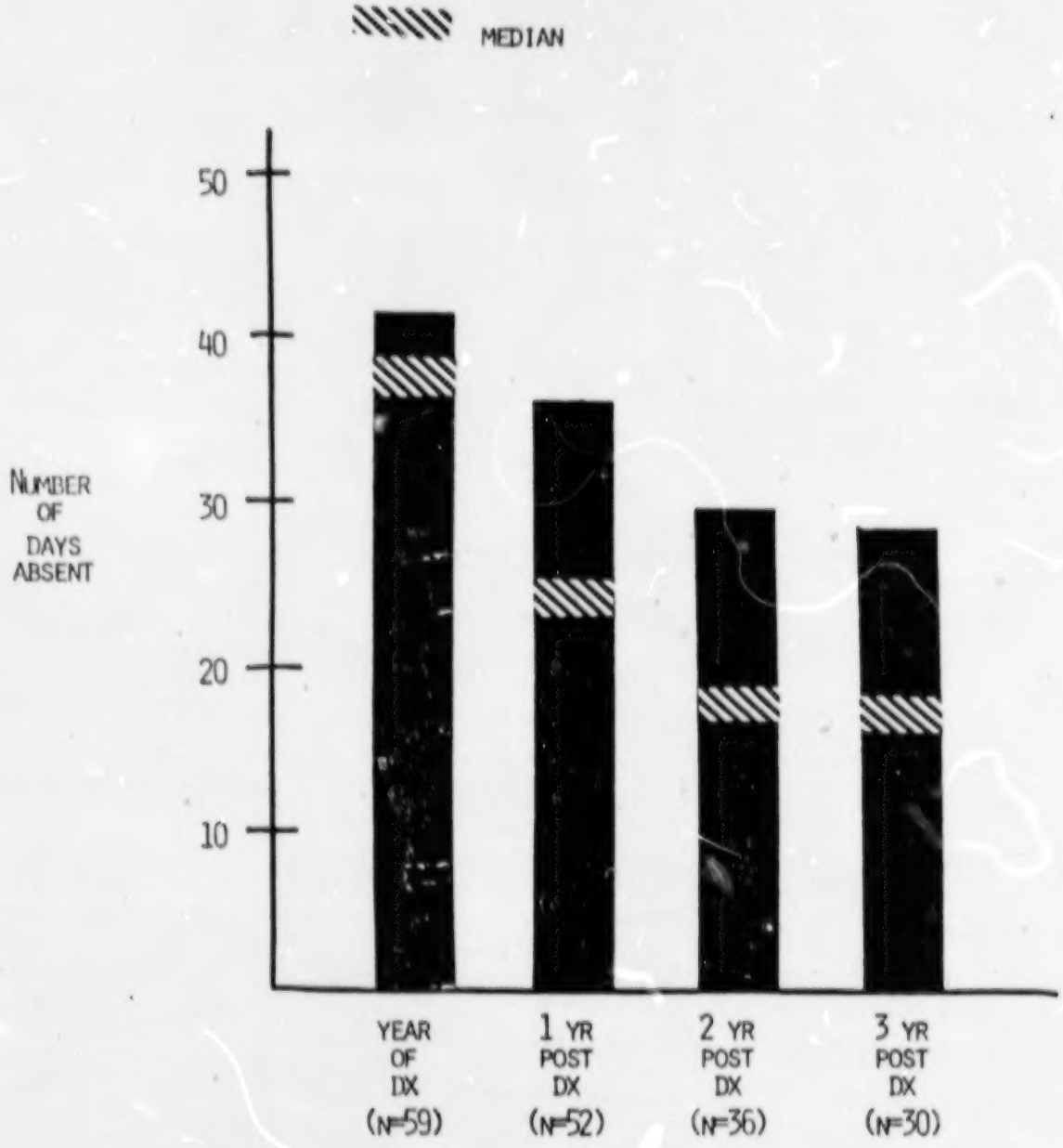

FIGURE 2

FREQUENCY OF PROBLEMS NOTED IN SCHOOL RECORDS OF CHILDREN WITH CANCER